

The Honorable Pamela Jo Bondi  
Attorney General for the State of Florida  
Florida Department of Legal Affairs  
PL-01 The Capitol  
Tallahassee, FL 32399-1050

Re: United States' Investigation of the State of Florida's Service System for Children with Disabilities Who Have Medically Complex Conditions, D.J. No. 204-18-212

Dear Attorney General Bondi:

We write to report the findings of the Civil Rights Division's investigation of the State of Florida (the "State") with respect to its system for delivering services and supports to children with disabilities, including those who have medically complex or medically fragile conditions.<sup>1</sup> During our investigation, we assessed the State's compliance with Title II of the Americans with Disabilities Act, 42 U.S.C. §§ 12131-12134 (the "ADA"), as interpreted by the Supreme Court in Olmstead v. L.C., 527 U.S. 581 (1999), requiring public entities to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs.

Our review of the State's system reveals that the State fails to meet its obligations under Title II of the ADA and its implementing regulations, 28 C.F.R. Part 35, by unnecessarily institutionalizing hundreds of children with disabilities in nursing facilities. Many children entering nursing facilities in the State are unnecessarily separated from their families and communities for years. With adequate services and supports, these children could live at home with their families or in other more integrated community settings. The State's policies and practices also place numerous other children who have medically complex or medically fragile conditions at risk of placement in nursing facilities and other institutional settings.

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<sup>1</sup> For the purposes of this letter, the United States adopts Florida's definition of "medically complex," found in Title 59G of the Florida Administrative Code: "'Medically complex' means that a person has chronic debilitating diseases or conditions of one (1) or more physiological or organ systems that generally make the person dependent upon twenty-four (24) hour-per-day medical, nursing, or health supervision or intervention." Fla. Admin. Code R. 59G-1.010(164). Medically fragile individuals are by definition medically complex. See Fla. Admin. Code R. 59G-1.010(165).

Consistent with the legal requirements set forth in the ADA, 42 U.S.C. § 12133, this letter serves to provide notice of the State's failure to comply with the ADA and of the minimum steps the State needs to take to meet its obligations under the law.

## I. SUMMARY OF FINDINGS AND CONCLUSIONS

We conclude that the State fails to provide services to children who reside in nursing facilities in the most integrated setting appropriate to their needs, and that the State's policies and practices put many other children with medically complex or medically fragile conditions at risk of placement in such facilities.

Hundreds of children are currently segregated in nursing facilities throughout Florida. They are growing up apart from their families in hospital-like settings, among elderly nursing facility residents and other individuals with disabilities. They live segregated lives—having few opportunities to interact with children and young adults without disabilities or to experience many of the social, educational and recreational activities that are critical to child development.

As part of our investigation, we visited the six large nursing facilities that house the vast majority of children who reside in such facilities in Florida. At each facility, we met with numerous children and received a substantial amount of data. From our review of this data, we found a wide range of diagnoses among the children residing in each facility. Yet we consistently identified children who are qualified to receive services in the community, and who would benefit from moving home with their families or to other community settings if appropriate supports were provided to them. We also spoke with many families who want to have their children living at home but report their frustration with State policies that inhibit their ability to do so.

Indeed, the State has planned, structured, and administered a system of care that has led to the unnecessary segregation and isolation of children, often for many years, in nursing facilities. For example, despite State and federal policies that require the State to evaluate children entering nursing facilities for appropriate placement in community-based settings, we found few examples of concrete efforts by the State to identify services that would enable children entering these facilities to return home to their families. As a result, many children continue to be separated from their families simply because the State has failed to identify or connect them to sufficient community-based services to meet their needs.

The State has also implemented policies and practices that impair access to medically necessary services and supports that would enable children to transition home or to other community-based settings. For example, we learned of many instances of the State reducing or limiting the availability of in-home services that had been prescribed as medically necessary by a child's physician, without reasonably considering the child's actual needs. And in the last several years, the State has made substantial cuts to programs designed to support children and adults with developmental disabilities in the community, leading to a years-long waiting list to access services. While cutting community-based services, the State has simultaneously implemented policies that have expanded facility-based care, including payment of an enhanced *per diem* rate to nursing facilities serving children who have medically fragile conditions. These policies put children with medically complex or medically fragile conditions who currently live in the

community at risk of placement in nursing facilities and other segregated institutional environments to receive necessary care.

Many family members of children in the facilities we visited have expressed their desire to bring their children home or see them move to a community-based setting. “I want my baby home,” said the mother of one three-year-old with Down syndrome and other conditions that require intensive assistance with respiratory and nutritional needs. Her daughter has been in a nursing facility since infancy. The mother expressed frustration that, in light of the services authorized by the State, she is only able to care for her child at home on certain weekends. Another mother traveled two hours round trip every day to visit her son, who resided in the children’s wing of a nursing facility for more than three years. Her son has a number of medical complications as a result of a near-drowning incident, and utilizes a ventilator for assistance with breathing. Although her son’s physician prescribed home health services to meet his needs at home, for years the State denied the amount of prescribed hours. Now that he receives the prescribed services, he lives at home with his family.<sup>2</sup>

Providing appropriate services and supports to these children in more integrated settings can be reasonably accommodated. The State’s service system already makes available in-home care services to Medicaid-eligible children, as required by the Early and Periodic Screening, Diagnostic and Treatment (“EPSDT”) provisions of the Medicaid Act, including home health services, private duty nursing, personal care services, and certain day treatment services.<sup>3</sup> In addition, the State currently provides other home and community-based services to individuals through its Medicaid program. Rather than ensuring the availability of these services when medically necessary and appropriate, the State’s system of services overly relies on institutional care in nursing facilities.

The State’s reliance on nursing facilities to serve these children violates their civil rights and denies them the full opportunity to develop bonds with family and friends and partake in educational,<sup>4</sup> social, and recreational activities in the community. By implementing the remedial

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<sup>2</sup> We learned during our visit that the State recently agreed to provide the prescribed amount of home health services to the family, but this decision came only after the family had filed a lawsuit against the state. See T.H. v. Dudek, No. 12-60460 (S.D. Fla., filed Mar. 13, 2012).

<sup>3</sup> The EPSDT mandate requires the State to provide services to Medicaid-eligible children under the age of twenty-one for all medically necessary treatment services, even if the State has not otherwise elected to provide such coverage to other populations. See 42 U.S.C. § 1396a(a)(43); 42 U.S.C. § 1396d(a)(4); 42 U.S.C. §§ 1396d(r)(1)-(5). The scope of the treatment to be provided is defined by 42 U.S.C. § 1396d(r) and includes “[s]uch other necessary health care, diagnostic services, treatment, and other measures described in [42 U.S.C. § 1396d(a)] . . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are [otherwise] covered under the state plan . . . .” 42 U.S.C. §§ 1396d(r)(1)-(5); see also 42 C.F.R. § 440.130.

<sup>4</sup> The Individuals with Disabilities Education Act requires that states receiving federal financial assistance must provide “a free appropriate public education” in the least restrictive environment to all children with disabilities residing in the State. 20 U.S.C. §§ 1412(a)(1), (5). As discussed below, we observed that many children with disabilities residing in Florida nursing facilities receive only limited educational services in settings that are not the least restrictive environment appropriate to their needs. See infra pp. 15.

measures described below, the State will correct identified ADA violations and other unlawful deficiencies and fulfill its commitment to individuals with disabilities.

## II. INVESTIGATION

On December 20, 2011, we sent your office a letter providing notice that the Department of Justice (the “Department”) had opened an investigation of the State with respect to the services it provides to children with disabilities under the age of twenty-one, including children who have medically fragile or medically complex conditions. We stated that the focus of our investigation was whether the State’s policies and practices regarding the services it provides these individuals violate federal law, including Title II of the ADA, 42 U.S.C. §12132, and its implementing regulations, as interpreted by the United States Supreme Court’s holding in Olmstead v. L.C., 527 U.S. 581 (1999). We further explained that the investigation was opened in response to information we received alleging that the State relies inappropriately and unnecessarily on nursing facilities, including those serving elderly individuals, as settings in which to provide services to children. In the same letter, we requested certain documents and other information related to our investigation. To date, and despite a number of requests, counsel from your office has declined to produce any information to the Department voluntarily.<sup>5</sup>

We have conducted a thorough investigation of the State’s system of services for children with disabilities—and particularly those who have developmental disabilities or who have medically complex or medically fragile conditions. We retained the services of an expert consultant with extensive experience arranging community-based services for children and youth in this population. With our expert, we visited a number of large nursing facilities that collectively serve more than two hundred children in Miami, Fort Lauderdale, Orlando, Tampa, and St. Petersburg.

We toured each facility and met extensively with administrators and staff. Children, ranging in age from infancy to early adulthood, are housed in rooms located along long hallways resembling hospital corridors. Children at some facilities wear identification bands at all times and are restricted to certain areas of the facility. For many, daily life occurs entirely within the facility. Upon arriving at one facility, we observed a significant number of elderly residents sitting in the facility’s entry hall and portico; children are housed on the second floor, and many only leave that floor for transportation to medical appointments or the occasional outing in the community. At another facility, the entryway to a primary outdoor space served as a smoking area for the adult and elderly residents. Nearby, an indoor central common area contained a number of children’s toys and a sitting area for elderly residents. At each facility, we observed children

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<sup>5</sup> In late January 2012, counsel for the State’s Agency for Health Care Administration (“AHCA”) contacted the Department and requested additional time to gather the requested data. We agreed to provide additional time, and said that we would speak again in two weeks to inquire as to the status of our request. On February 6, 2012, counsel for AHCA informed us that the matter had been referred to the State Attorney General’s office for coordination among the several State agencies having custody of data responsive to the Department’s request. On the same day, we contacted counsel from your office, who informed us that a meeting among these agencies had been scheduled for later in the week, and that he would have further information regarding the State’s response on February 13, 2012. Subsequently, counsel from your office communicated that the State would not provide any information responsive to the Department’s request without a subpoena. At his request, we wrote counsel on March 23, 2012 to explain the Department’s investigative authority under the ADA and to reiterate the Department’s request that the State cooperate with this investigation. We requested a response by April 6, 2012, but to date we have not received a response.

engaging in various activities scheduled by facility staff, watching television in a common area, or sitting unattended in their beds.

During our visits we also collected certain information related to the children residing in these facilities. Based on this data and other data routinely submitted to the federal government by these facilities, we have reviewed a substantial amount of information regarding these children, including each child's length of stay in the facility. We and our consultant have also reviewed hundreds of pages of records, including a large number of care plans written by the facilities and periodic assessments conducted by the State.

We also spoke with family members of many of these children. They shared their stories with us, and many expressed their desire to raise their children in an environment that fosters involvement and participation in the community, close to the child's family and loved ones. They also shared their frustration with the State's administration of services and expressed the general perception that the State does not arrange for services in a manner that would allow their children to remain safely at home.

Families who care for children with medically complex conditions in their homes expressed similar concerns. Although their children currently access community services that allow them to remain at home, the families have faced recent efforts by the State to reduce the availability of these services. For example, a number of families told us of their tireless efforts to ensure their children receive the amount of in-home nursing hours that their children's physicians have prescribed. Repeatedly, however, the State has denied or reduced these medically necessary services. These families told us that the stress added by frequent reductions has impinged on their ability to care for their children.

During our examination of the range of services available within the State's system, we met or held telephone conferences with numerous providers of community-based services for children with disabilities, including those that serve children who have medically complex or medically fragile conditions. We also interviewed stakeholders within the system and a number of advocates for families of children and youth with disabilities. Many within these groups articulated frustrations similar to those of the families with whom we spoke. Specifically, they informed us that the State's administration of its service system is driven by considerations other than the health, safety, wellbeing, and development of the children being served, and as a result, families that are able, with appropriate supports, to care for their children at home may be stretched to the point of admitting their child to a nursing facility or other institutional setting.

### **III. BACKGROUND**

The State provides services to children with developmental disabilities and those who have medically complex or medically fragile conditions through a number of State agencies, including the Department of Health ("DOH"), the Agency for Health Care Administration ("AHCA"), the Department of Children and Families ("DCF"), and the Agency for Persons with Disabilities ("APD"). Within DOH, the Children's Medical Services ("CMS") program has lead responsibility for facilitating collaboration among these agencies to arrange for long-term care services for children with certain special health care needs, including medically complex and/or medically

fragile conditions.<sup>6</sup> Collectively, representatives from each agency participate in a Children's Multidisciplinary Assessment Team ("CMAT"), which convenes for each eligible child under the age of twenty-one identified as medically fragile or medically complex and needing certain long-term care services.<sup>7</sup> For children who receive services from several different agencies, CMAT staff is directed to work collaboratively with care coordinators from each agency to ensure that the child's needs are met.<sup>8</sup>

#### A. Placement of Florida Children in Nursing Facilities

During our investigation we learned that through the CMAT process, the State has overseen the placement of hundreds of children into nursing facilities.<sup>9</sup> For a majority of the children referred to these facilities, the State pays an enhanced rate of over \$500 per day per child, which is more than double what the facility receives from the State to serve elderly individuals and other adults.<sup>10</sup>

Through our visits to multiple facilities, reviews of resident records, and conversations with family members, we found that a significant number of children are referred to a CMAT while hospitalized and placed in nursing facilities directly from the hospital.<sup>11</sup> For example, one ten-year-old child sustained a near-drowning accident at the age of six and was discharged from the hospital to a nursing facility, where she has remained ever since. Her mother lives hundreds of miles away from the facility, but tries to visit her daughter as often as she can. She told us, "if I had the resources to take care of my [child], you can be ... sure [my child] would be living with me right now." Another five-year-old child who has quadriplegia and respiratory complications resulting from a car accident has lived in a facility for three years since the accident. His mother wants to bring him home but reports that she has been told that the waiting time for community-based services is five to ten years. She told us, "I cry all the time thinking of [my child]....There should be something out there to help children come home."

Other children were placed in a nursing facility from home after their families were unable to obtain necessary services and supports through the State Medicaid program. One eighteen-year-old who was born with cerebral palsy moved with her mother to Florida to be closer to other family members in 2007. Upon arriving in Florida, the family discovered that the State would not provide community-based services that the child had previously relied upon to live in the

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6 See Fla. Stat. § 20.43, § 391.016, § 391.026; See also DOH, CMS, DCF & AHCA, CMAT Statewide Operational Plan 1 (2010), available at [http://www.cms-kids.com/home/resources/documents/cmat\\_plan.pdf](http://www.cms-kids.com/home/resources/documents/cmat_plan.pdf).

7 See CMAT Statewide Operational Plan, at 1-2.

8 See *id.* at 27.

9 See Fla. Admin. Code R. 59A-4.1295(3) (requiring recommendation from CMAT prior to a child's admission to a nursing facility).

10 See AHCA Website, Nursing Home Supplemental Payments, [http://ahca.myflorida.com/medicaid/cost\\_reim/nhsp.shtml](http://ahca.myflorida.com/medicaid/cost_reim/nhsp.shtml) (last visited July 11, 2012); AHCA Website, Nursing Home Rates, [http://ahca.myflorida.com/medicaid/cost\\_reim/nh\\_rates.shtml](http://ahca.myflorida.com/medicaid/cost_reim/nh_rates.shtml) (last visited July 11, 2012).

11 We also learned that some children in the custody of the State had been admitted to a facility through DCF.

community. As a result, her mother had to place her in a nursing facility to meet her medical needs. The grandmother of another nineteen-year-old young man diagnosed with traumatic brain injury told us that her family had no choice but to place their child in a nursing facility because of the State's waiting list for community-based services. "If we took him home, we wouldn't have gotten any help," she told us. The young man still resides at the nursing facility, but is working towards obtaining a degree from a local high school.

Prior to each child's admission to a nursing facility, the State is responsible for assessing whether placement in a community-based setting would be appropriate. The Pre-Admission Screening and Resident Review ("PASRR")<sup>12</sup> is a two-step evaluation process, required by federal law, that is designed among other things to screen individuals entering nursing facilities for intellectual disabilities or related conditions (a "Level I" screening), determine whether the individual needs nursing facility services, assess whether placement in a community setting would be an appropriate alternative, and identify specialized services required to meet the individual's needs (a "Level II" assessment).<sup>13</sup> If, after a Level I PASRR screening, it is suspected that a child has an intellectual disability or a related condition, the CMAT is tasked with referring the child to APD for a Level II assessment.<sup>14</sup> According to guidance from the State, the child may be admitted to the facility only after APD has completed a Level II assessment of the child.<sup>15</sup>

The PASRR assessment is supposed to determine whether "the individual's total needs are such that his or her needs can be met in an appropriate community setting" and "identifies the specific services which are required to meet the evaluated individual's needs . . . ."<sup>16</sup> The Medicaid Act further requires that an individual must be promptly re-evaluated to determine whether her needs can be met in the community when there has been a significant change in physical or mental condition.<sup>17</sup> On paper, State policies are similar—the CMAT must evaluate the need for continued facility placement six months after a child has been placed in a nursing facility.<sup>18</sup> Thereafter, the CMAT must conduct a follow-up meeting at least annually to re-assess

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12 The federal Nursing Home Reform Act requires that states develop and implement a Preadmission Screening and Resident Review ("PASRR") program for all Medicaid-certified nursing facilities. 42 U.S.C. § 1396r(e)(7); 42 C.F.R. §§ 483.100 to 483.138.

13 See 42 U.S.C. § 1396r(e)(7); 42 C.F.R. §§ 483.100 to 483.138.

14 See CMAT Statewide Operational Plan, at 67-68.

15 See id. at 68.

16 42 C.F.R. §§ 483.128(i)(3), 483.132(a)(1). According to the PASRR Technical Assistance Center, established by contract with the Centers for Medicare and Medicaid Services, "The Level II [assessment] must . . . determine whether the individual's needs would be better met by living in the community whether or not those services are currently available. Even if [nursing facility] placement is ultimately the most practical option, the Level II should identify the services the individual would need to live in the community, even if those services do not exist or are inaccessible . . . ." PASRR Technical Assistance Center, PASRR in Plain English, <http://www.pasrrassist.org/resources/pasrr-plain-english> (updated May 10, 2011).

17 42 U.S.C. § 1396r(e)(7)(B)(iii).

18 See CMAT Statewide Operational Plan at 70.

the child's status.<sup>19</sup> A more frequent meeting is required if there is a significant change in the child's clinical status or a meeting is requested.<sup>20</sup>

Despite these pre-admission and ongoing review requirements, in our review of data we noted a large number of children who had indications of an intellectual or developmental disability but for whom PASRR evaluations had apparently not been performed, either initially or after there had been an apparent change in the child's condition.<sup>21</sup> We learned that CMAT meetings are often done remotely, and that a CMS representative visits the facility only periodically. From our review, we observed that for many children the State has little, if any, active involvement in identifying more integrated service options for the child. Instead, the State largely relies on social workers employed by the nursing facilities to make recommendations for alternative services in the community.<sup>22</sup> Yet a number of the social workers we spoke with showed a lack of familiarity with many of the State's home and community-based services that would allow children to live at home with their families.

When a child in a nursing facility turns eighteen years of age, the CMAT is to begin transition planning for the transfer of responsibility to the local Department of Elder Affairs, which gains responsibility for the individual upon his or her twenty-first birthday.<sup>23</sup> At a number of facilities, we learned that after their twenty-first birthday, some young adults are simply transferred down the hall to a different ward of the facility and housed among elderly residents. We also received information that individuals have been discharged from one nursing facility to another at their twenty-first birthday.

Many children and young adults who have been placed in these facilities remain there for a very long time, even when it is apparent that their medical conditions would permit return to the community with appropriate supports. Among the facilities we visited, the average length of stay for children is over three years. More than fifty children had resided in a facility for over five years. And a number of children had been in a facility for a decade or longer, including some who entered a facility as toddlers or young children and who remain in the facility as adolescents.

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<sup>19</sup> See *id.*

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*Id.* For children who receive additional Medicaid services that are not included in the nursing facility's *per diem* rate, a CMS nurse care coordinator must visit the child once every six months to "review the child's plan of care and progress notes, collaborate with the nursing facility care coordinator to ensure appropriateness of care and maintain contact with the family." *Id.* at 71.

<sup>21</sup> Further, children who were admitted to a nursing facility before the age of three have allegedly not been screened through the PASRR process because of a State policy that children under three may not, by definition, be diagnosed with mental illness or an intellectual or developmental disability. See CMAT Statewide Operational Plan at 68; Children's Medical Services, Weekly Update, March 7, 2008, available at [www.cms-kids.com/providers/early\\_steps/memos/memo\\_03\\_07-08.pdf](http://www.cms-kids.com/providers/early_steps/memos/memo_03_07-08.pdf).

<sup>22</sup> See generally, CMAT Statewide Operational Plan at 72; see also Fla. Admin. Code R. 59A-4.1295(5)(c) (delegating certain responsibilities to facility staff "to facilitate a smooth transition from the nursing facility to the home or other placement").

<sup>23</sup> See CMAT Statewide Operational Plan, at 71-72.





## B. Home-Based and Community-Based Services

The children in nursing facilities in Florida have a range of diagnoses, but with appropriate services and supports, these children could have their care needs met at home or in other community-based settings. It is apparent, however, that families of many of these children have been told without sufficient basis that their children are not capable of living at home, or have been given very little information, if any, about alternative services that could help support their child in the community.

The specific services that any child will need to address their care needs must be prescribed by the child's treating professionals after an individual assessment, and targeted to meet the child's specific needs. Though their care needs vary, most children who have medically complex conditions are totally dependent on assistance from others to perform activities of daily living, such as eating, bathing, or dressing, and require periodic monitoring and regular therapies. These children will generally require services in the form of a personal care attendant for at least some portion of each day to assist with these needs. In addition, many children with medically complex conditions require frequent skilled nursing services for a set number of hours per day to assist with nutritional and respiratory needs, including care associated with a feeding tube or a ventilator. Other children have high variability in their care needs, including regulation of body temperature or assistance with respiratory technology that requires continuous observation and intervention and which may require ongoing exercise of medical judgment.

The State offers a number of home-based services capable of serving children just like those who reside in nursing facilities in Florida. The State also offers placement in homelike settings other than the child's family home when the child's family is unable to care for the child at home.<sup>24</sup> If authorized by the State, these services permit children and young adults to remain at home with their families or in other community-based settings. We found, however, that the State administers these services in a manner that restricts their availability, resulting in limited or no possibility for children in nursing facilities to transition to these services, and placing other children in the community at risk of entry to a nursing facility because they are unable to access the community-based services that they need.

### 1. *Medicaid State Plan Services*

Some community-based services are available through the Medicaid State Plan, including home health services such as private duty nursing and personal care services, and medically

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<sup>24</sup> Medical Foster Care ("MFC"), for example, is a service coordinated between AHCA, CMS, and DCF to provide family-based care for medically complex children under the age of twenty-one who have been determined unable to safely receive care in their own homes. See DOH, DCF, & AHCA, MFC Statewide Operational Plan, at 1-1 (2009), available at [http://www.cms-kids.com/home/resources/documents/mfc\\_state.pdf](http://www.cms-kids.com/home/resources/documents/mfc_state.pdf). The purpose of the MFC program is "[t]o enhance the quality of life for medically complex and medically fragile foster children, allowing them to develop to their fullest potential . . . [and to] provide a family-based, individualized, therapeutic milieu of licensed medical foster homes to reduce the high cost of long-term institutionalization of medically complex and medically fragile foster children." *Id.* To be eligible for the MFC Program, an individual must be in the custody of DCF through a court order or a voluntary placement agreement. See Fla. Admin. Code R. 65C-28.007 (establishing procedures for voluntary out-of-home care).

necessary therapies.<sup>25</sup> In recent years, however, the State has implemented restrictions on the availability of these services. The State has implemented utilization review processes, for example, that authorize reviewers employed by a State contractor to reduce or alter the in-home nursing services prescribed by a child's physician.<sup>26</sup> These processes are designed to achieve cost savings and to avoid unnecessary or duplicative services. Families, providers, and advocates informed us, however, that these processes are being administered in a way that may lead to increasing the State's costs for the care of children with disabilities—as reduced availability of community-based care results in more frequent hospitalizations and emergency room visits, and long-term institutionalization in nursing facilities.

Additionally, during our investigation we learned of instances of the State's utilization review process being applied irrationally or without appropriate consideration of the child's needs, resulting in service authorizations below the level required to safely meet a child's care needs. For example, one ten-year-old girl with traumatic brain injury who lives at home with her mother and two siblings has had her requests for prescribed in-home care services denied, and her services thereby reduced, during at least four reviews since 2010. These reductions have occurred without any change in her medical condition. Her mother fears that without sufficient medically necessary in-home care services their family will no longer be able to care for their daughter at home, and they will be forced to place the child in a nursing facility.<sup>27</sup> She informed us that she will continue to push for the services her daughter needs saying, "I love her and I want her to be home with her family . . . I don't think it's fair to put her in an institution."

Every six months, the families of children with prescribed in-home nursing services must recertify that those services are necessary. We learned of many instances of the State repeatedly denying or reducing prescribed hours of in-home nursing at each six-month recertification period, even when there had been no change in the parent's availability or ability to provide care, or the child's medical condition. The parents of one eight-year-old child with a medically fragile condition, for example, both work full time jobs, but want to make sure that their child has safe and appropriate medical care while at home. The child's mother informed us that the services prescribed by her child's physician as medically necessary have been denied or reduced thirteen times since 2006, even though her child's condition has not changed. She told us, "[i]t's a fight and a battle all the time... [b]y the time one [recertification period] finishes it's time to start all over again." The mother of another eighteen-year-old with cerebral palsy told us that she was "so overwhelmed" with the existing care she provided to her son that she was unable to even attend a hearing contesting further service reductions.

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<sup>25</sup> See generally, AHCA, Home Health Services Coverage and Limitations Handbook, available at [http://portal.flmmis.com/FLPublic/Portals/0/StaticContent/Public/HANDBOOKS/CL\\_08\\_080701\\_Home\\_Health\\_ver\\_1.2.pdf](http://portal.flmmis.com/FLPublic/Portals/0/StaticContent/Public/HANDBOOKS/CL_08_080701_Home_Health_ver_1.2.pdf).

<sup>26</sup> Fla. Stat. § 409.905(4)(b); see also AHCA Contract No. MED128; EQ Health Solutions, Florida Division Website: <http://fl.eqhs.org/> (last visited July 2, 2012).

<sup>27</sup> See also discussion *infra*, pp. 18-20.

## 2. *Home and Community-Based Waiver Programs*

In addition to in-home nursing and other services available through the Medicaid State Plan, other services are available only to individuals who are enrolled in one of the State's size-limited waiver programs for individuals with developmental disabilities. Since July 2005, the number of individuals on the waiting list for services under these programs has grown from 14,629 to more than 21,000 in March 2012, and more than half of the individuals on the list have waited for five years or more.<sup>28</sup> Pursuant to current state policies, a child in a nursing facility would not qualify for prioritization on this waiting list.<sup>29</sup> Children with medically complex conditions who currently live at home and who may qualify for these waiver services face the barrier of a years-long waiting list for services.

Despite the growth of demand for waiver services, the number of individuals actually enrolled in these programs has decreased by several thousand in the last several years.<sup>30</sup> The State's payments to providers of services under these programs have also shrunk. In 2011, for example, APD announced that payment rates to all providers of community-based services under the State's waiver programs for individuals with developmental disabilities would be reduced by 15% to respond to a legislative decrease in funding.<sup>31</sup>

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28 See *Dykes v. Dudek*, No. 11-00116 (N.D. Fla.), Exhibit I to Pls.' Mot. for Sum. J. (Defs.' Resp. to Interrog.), ECF No. 125-9, at 4; *APD Quarterly Report*, May 2012, at 10.

29 See Fla. Admin. Code R. 65G-11.002 (3) (incorporating the crisis criteria specified in Fla. Admin. Code R. 65G-1.047); Ex. I to Pls.' Statement of Facts, Defs' Answer to Interrog., *Dykes v. Dudek*, No. 11-00116 (N.D. Fla. May 2, 2012), ECF No. 125-9 ("since 2006 enrollment has been limited to individuals who are in crisis."). Pursuant to a budgetary proviso established by the State legislature, AHCA is permitted to transfer funding from nursing facilities to enroll additional individuals onto a number of the State's waivers serving persons with physical disabilities. But this program would not permit children in nursing facilities with developmental disabilities to access waiver services sufficient to meet their needs, because the services provided in these waivers are not targeted to individuals with developmental disabilities. See Ch. 2011-69, Laws of Florida, Specific Appropriation 208. In addition, by definition the Aged and Disabled Adult Waiver is open only to individuals aged 18 and over, rendering it out of reach for a large number of younger individuals currently in nursing facilities, regardless of their disability. See AHCA, *Alternatives to Nursing Homes*, <http://apps.ahca.myflorida.com/nhcguide/alternatives.shtml#AgedandDisabledAdultWaiverProgram> (last visited July 13, 2012). A similar budgetary proviso permits transfer of funds for individuals residing in Intermediate Care Facilities, but not nursing facilities, to waiver programs for individuals with developmental disabilities. See Laws of Florida 2011-69, Specific Appropriation 206; Laws of Florida 2012-118, Specific Appropriation 222.

30 See *APD Quarterly Report*, Nov. 2007, at 2; *APD Quarterly Report*, May 2012, at 2. The State is also transitioning all individuals currently on these waivers to a single new waiver that we learned may result in a reduction in the amount of waiver-funded services available to an individual. See Fla. Stat. § 393.0662; *APD Quarterly Report*, May 2012, at 2; *APD Cost Containment Plan FY 2011-12*, at C-2, available at: <http://apdcares.org/publications/legislative/docs/apd-cost-containment-plan-2011-2012.pdf> (noting that implementing new waiver may lead to service decreases).

31 See APD, *Plan Pursuant to Section 393.0661(7), F.S. For Adjustments Necessary to Comply With the Availability of Monies Provided to the Agency for Persons with Disabilities in the General Appropriations Act*, available at <http://apd.myflorida.com/news/news/2011/emergency-plan.pdf>.

#### IV. FINDINGS

We conclude that the State fails to provide services to children who reside in nursing facilities in the most integrated setting appropriate to their needs as required by the ADA. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d). Instead, the State administers its system of services in a manner that unnecessarily segregates hundreds of children in nursing facilities and fails to make available sufficient services in integrated, community-based settings. See 28 C.F.R. §§ 35.130(b), (d). As a result, children who could be served in the community with the types of services and supports that exist in the State’s service system are needlessly institutionalized, often for very long periods of time, rather than having the opportunity to live at home with their families or in other community-based settings. The State’s policies also place many other children who have medically complex or medically fragile conditions at risk of placement in nursing facilities or other segregated settings. The State must take action to remedy these violations.

##### A. The ADA Requires States to Serve Individuals with Disabilities in the Most Integrated Setting Appropriate to their Needs.

The segregation and isolation of children in nursing facilities and the failure to ensure that these individuals have opportunities to move to more integrated settings violates their civil rights. Congress enacted the ADA in 1990 “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” 42 U.S.C. § 12101(b)(1). Congress found that “historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” Id. § 12101(a)(2). For these reasons, Congress prohibited discrimination against individuals with disabilities by public entities:<sup>32</sup>

[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

Id. § 12132.<sup>33</sup>

One form of discrimination prohibited by Title II of the ADA is a violation of the “integration mandate.” The integration mandate arises out of Congress’s explicit findings in the

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32 A “public entity” includes any State or local government, as well as any department, agency, or other instrumentality of a State or local government. Title II applies to all services, programs, and activities provided or made available by public entities, including through contractual, licensing, or other arrangements. 42 U.S.C. § 12131(1); 28 C.F.R. § 35.102(a); 28 C.F.R. § 35.130(b).

33 Nearly 20 years before enacting the ADA, Congress recognized that society historically had discriminated against people with disabilities by unnecessarily segregating them from their families and communities, and in response, enacted Section 504 of the Rehabilitation Act of 1973, which forbids any program receiving federal aid from discriminating against an individual by reason of a handicap. See 28 C.F.R. § 41.51(d) (“[r]ecipients [of federal financial assistance] shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons”). Our findings and conclusions in this letter also implicate the State’s compliance with Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 et seq.

ADA, the Attorney General's regulations implementing Title II,<sup>34</sup> and the Supreme Court's decision in Olmstead, 527 U.S. at 587. In Olmstead, the Supreme Court held that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate, (b) the affected persons do not oppose community-based treatment, and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of other persons with disabilities. Id. at 607.

In so holding, the Court explained that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Id. at 600. It also recognized the harm caused by unnecessary institutionalization: "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." Id. at 601.

The ADA's protections are not limited to those individuals who are currently institutionalized. The integration mandate also prohibits public entities from pursuing policies that place individuals at risk of unnecessary institutionalization. See M.R. v. Dreyfus, 663 F.3d 1100, 1116-17 (9th Cir. 2011); see also Fisher v. Oklahoma Health Care Auth., 335 F.3d 1175, 1181 (10th Cir. 2003) (noting that "nothing in the Olmstead decision supports a conclusion that institutionalization is a prerequisite to enforcement of the ADA's integration requirements").

Our investigation has produced substantial evidence that the State fails to provide services to hundreds of children currently in nursing facilities in the most integrated setting appropriate to their needs, and places many others at risk of institutionalization, in violation of its obligations under the ADA and Olmstead.

#### B. Nursing Facilities Are Segregated, Institutional Settings

The nursing facilities in which hundreds of Florida's children and young adults currently reside are segregated, institutional settings. Cf., e.g., Day v. District of Columbia, No. 10-cv-2250-ESH, 2012 WL 456491, at \*22 (D.D.C. 2012) (denying motion to dismiss ADA claim regarding institutionalization in nursing facilities); Conn. Office of Prot. & Advocacy for Persons with Disabilities v. Conn., 706 F. Supp. 2d 266 (D. Conn. 2010) (same); Joseph S. v. Hogan, 561 F. Supp. 2d 280 (E.D.N.Y. 2008) (same); Long v. Benson, No. 4:08cv26-RH/WCS, 2008 WL 4571904, at \*3 (N.D. Fla. Oct. 14, 2008) (certifying class of individuals who were institutionalized in nursing homes); Colbert v. Blagojevich, No. 07 C 4737, 2008 WL 4442597, at \*10 (N.D. Ill. Sept. 29, 2008) (same); Rolland v. Cellucci, 52 F. Supp. 2d 231 (D. Mass. 1999) (denying motion to dismiss ADA claim regarding institutionalization in nursing facilities). As the Supreme Court has recognized, undue segregation causes harm to individuals with disabilities who are unnecessarily institutionalized. See Olmstead, 527 U.S. at 601.

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<sup>34</sup> The regulations provide that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). See also 28 C.F.R. § 41.51(d). The preamble discussion of the "integration regulation" explains that "the most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible[.]" 28 C.F.R. § 35.130(d), App. B. at 673 (2011).

The children and young adults in the facilities we visited live segregated lives. They spend most of their days residing in shared rooms with other individuals with disabilities, participating in meals and activities with other individuals with disabilities, and having only limited interaction with individuals without disabilities. Many of the residents' families live in other areas of the State, leaving the children hundreds of miles from family and loved ones. Among the six facilities we visited, five serve elderly individuals as well as children and young adults. The interiors of these facilities resemble hospitals—housing children in rooms with at least one, and sometimes up to three, other individuals. Some facilities house upwards of three hundred residents, including children, young adults, and elderly individuals. At one large nursing facility housing nearly 250 children and adults, we observed children and young adults with disabilities sitting in the hallways. They waited for staff to come by to usher them to activity sessions while they watched the activities of other residents and staff. Most sat quietly and occasionally reached out to make contact with a passing staff member. Other children remained in their beds.

Institutionalization does not provide the stimulation and variety of interactions that occur in the community—the kind of interactions that contribute to the full development of a child or young adult. Indeed, residents' choices regarding how they spend their day appear severely limited. Activities offered at a number of the facilities are scheduled by staff and often involve young children, young adults, and elderly individuals intermixing, regardless of the activity being offered. Many of the residents we observed were left in their beds or mobility devices for long periods at a time with limited access to the type of interactions that promote physical, psychological and social development.

The educational opportunities available to children and young adults who are placed in these facilities are also quite limited. A large number of children participate in public school districts' hospital/homebound programs, which serve children who are deemed ineligible to participate in an integrated classroom environment for medical or other reasons. For these students, the facilities offer a room or area in the facility where children are given classroom instruction in small groups or one-to-one for short periods of time. From our review, it appeared that many children were offered only forty-five minutes of educational activities per day, several days per week.<sup>35</sup>

A substantial number of children and young adults in these facilities have families who visit often and who offer undeniable levels of care and support. Many families, however, live far from the institutions and for that reason it is difficult to visit regularly. Other children and young adults are in the custody of the State and do not have active familial involvement. For these individuals, their interaction with other individuals without disabilities appears limited to infrequent community outings or in-facility visits from community volunteers.

#### C. Children and Young Adults Currently Residing in Florida Nursing Facilities Could Be Served In More Integrated Settings

States have an obligation to provide services in community-based settings where such placement is appropriate for, and not opposed by, persons with disabilities. Olmstead, 527 U.S. at

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<sup>35</sup> The Individuals with Disabilities Education Act requires states to provide “a free appropriate public education” in the least restrictive environment to all children with disabilities. See 20 U.S.C. §§ 1412(a)(1), (5).

607. The State already offers community-based programs that serve children just like those residing in nursing facilities, but which permit children to live in their family home or in an integrated, community-based setting. During our investigation we met with or had telephone conversations with a number of providers of these services. In contrast with children residing in nursing facilities, children receiving home or community-based services generally have their own specially modified room, enjoy the presence of their families throughout the day, and are able to engage in more frequent activities in their neighborhoods and communities.

Most, if not all, of the children and young adults currently receiving long-term care services in nursing facilities in Florida could be served in more integrated settings. After meeting and observing a large number of residents and reviewing a substantial number of records, our expert has found that children and young adults currently receiving services in the facilities we visited are not meaningfully different than children and young adults who currently live in more integrated community-based settings. In fact, a number of the children and young adults at certain facilities periodically leave the facility to attend school on a daily basis, or are taken home by their families on weekends. For these individuals particularly, we discerned no apparent reason for their continued stay in the facility.

Indeed, almost all of the nursing facility administrators we met with said that if the resources were in place to support families taking their children home, they could send a substantial number of children home on a permanent basis. One administrator noted that physical support in the form of home health services is “critical” to meet needs at home for many families. The administrator stated that “most of our families would take their kids home if [the families] had some support.” The administrator added that most parents who work “don’t have the kind of support” to care for a medically complex child without assistance.

Within Florida there are providers of community-based services for children and young adults with diagnoses and needs similar to those of many individuals currently receiving services in skilled nursing facilities. Some providers serve children and young adults in the community who have successfully transitioned from nursing facilities. When we met with a number of these providers, they said that with appropriate services and supports most, if not all, children who are receiving services in skilled nursing facilities could be transitioned home or to another community-based setting.

Additionally, there are numerous children in other states, with needs similar to those of the children institutionalized in Florida nursing homes, who are being served successfully in community-based settings through those states’ Medicaid waiver programs for persons who are medically fragile or technologically dependent. With the supports provided through these waivers and other Medicaid services, hundreds, and in some states thousands, of families are able to stay united and children and young adults are able to participate in educational, social, and recreational activities in their own communities. The children in Florida’s nursing facilities and their families are no different.

D. The State Violates the ADA by Failing to Serve Qualified Individuals with Disabilities in the Most Integrated Setting Appropriate to their Needs



Under the ADA, public entities are required to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). A state violates the ADA where it administers its programs or services in a manner that unnecessarily segregates persons with disabilities in privately owned facilities. 28 C.F.R. § 35.130(b) (prohibiting public entities from using contractual or other arrangements, or utilizing criteria or methods of administration, that have the effect of subjecting qualified individuals with disabilities to discrimination); see also Disability Advocates v. Paterson, 598 F. Supp. 2d 289, 317 (E.D.N.Y. 2009) (“It is immaterial [for purposes of Title II liability] that DAI’s constituents are receiving mental health services in privately operated facilities.”), overruled on other grounds by Disability Advocates, Inc. v. Cuomo, 675 F.3d 149 (2d Cir. 2012); Rolland v. Celluci, 52 F. Supp. 2d 231, 237 (D. Mass. 1999) (holding that it is immaterial for purposes of Title II ADA claim that plaintiffs lived in private nursing facilities, rather than state-operated facilities).

In addition to those currently harmed by unnecessary institutionalization, many other children in the State are at risk of needless segregation in violation of the ADA. Courts have determined that the ADA’s integration mandate not only applies to individuals who are currently institutionalized, but also to individuals who are at risk of unnecessary institutionalization because of a public entity’s administration of its services. See M.R. v. Dreyfus, 663 F.3d 1100, 1114 (9th Cir. 2011) (finding risk of institutionalization when state reduced hours of in-home personal care services); Radaszewski v. Maram, 383 F.3d 599, 612 (7th Cir. 2004) (ADA applied to individual at risk of entering a nursing home); Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1181-82 (10th Cir. 2003) (same); Pitts v. Greenstein, 2011 WL 2193398, at \*2 (M.D. La. 2011) (“The ADA’s and Section 504’s ‘integration mandate’ prohibits a state from increasing an individual’s risk of institutionalization if reasonable accommodations are available.”); Brantley v. Maxwell-Jolly, 656 F. Supp. 2d 1161, 1170 (N.D. Cal. 2009) (stating that the risk of institutionalization is sufficient for a violation of the ADA); M.A.C. v. Betit, 284 F. Supp. 2d 1298, 1309 (D. Utah 2003) (same). State actions that place individuals with disabilities at serious risk of institutionalization violate the ADA unless a community placement cannot be reasonably accommodated.

The State has enacted legislation declaring that:

the greatest priority shall be given to the development and implementation of community-based services that will enable individuals with developmental disabilities to achieve their greatest potential for independent and productive living, enable them to live in their own homes or in residences located in their own communities and permit them to be diverted or removed from unnecessary institutional placements.

Fla. Stat. § 393.062; see also Fla. Stat. § 409.145 (policy preventing separation of children from their families and promoting reunification of families who have had children placed in foster homes or institutions). Despite enacting policies prioritizing community-based services and unification of families, the State administers its system of care in a manner that results in the unnecessary and prolonged institutionalization of children with disabilities in nursing facilities, separating them from their families for years.

1. *The State Fails to Assess Children Entering Nursing Facilities for Community*

*Placement and Does Not Adequately Arrange for Transition to Community Settings*

As noted above, State and federal policies require assessment of individuals with disabilities prior to their admission to a nursing facility to determine whether community-based services would be appropriate. Our investigation has revealed evidence that the State fails to take appropriate measures to ensure that children who have been placed in a nursing facility are considered for alternative placements in a timely manner, both before their admission to the facility and during on-going assessments and reviews.

From our conversations with nursing facility staff, review of residents' records, and interviews of stakeholders, we observed a number of pathways through which many children and young adults enter a nursing facility: placement in a facility for recovery after a hospital stay; placement after the State, through DCF, has taken custody of the child; and placement by the child's family after the family has exhausted its resources or has been unable to access necessary services from other sources, including other State-funded Medicaid services. Regardless of the individual's pathway into the facility, their entrance to the facility, and continued stay, is contingent upon the State's recommendation and approval through the CMAT process.<sup>36</sup>

State and federal requirements for pre-admission assessment as to the appropriateness of community-based services do not appear to be consistently followed. As a result, most of the children and young adults who have been placed in facilities remain there for a very long time, even when it is apparent that their medical conditions would permit return to the community with appropriate supports. Our review of the State's assessments of current residents reveals that a substantial number of children and young adults receive little or no realistic discharge or transition planning from the State. We found a number of instances where the CMAT held its annual review despite being unable to reach the parent or guardian. Individual plans of care, written by the facilities, often contained a discharge planning component that presented few, if any, concrete goals designed to identify the steps necessary to successful discharge. Even more troubling, a number of children and young adults in these facilities are currently in the custody of the State through DCF even though, as noted above, the State has community-based services available to children in the foster care system in the form of medical foster care. We encountered little evidence of efforts on the part of the State to attempt to develop a plan for these children to transition to more integrated settings.

One nursing facility staff member told us, "once we get the children, very few of them go home." Another reported that while some families of children entering his facility have the impression that their child can be returned home, "then they stay." Data provided by the facilities we visited confirm these observations. As noted above, the average length of stay for children in these facilities is over three years, and some children have literally "grown up" in the facility.

When individuals in institutions do not oppose, and especially when they affirmatively request, community placement, it is the State's responsibility to develop and implement prompt and effective steps to transition them to and serve them in integrated community settings. See Messier v. Southbury Training Sch., 562 F. Supp. 2d 294, 322-23 (D. Conn. 2008).

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<sup>36</sup> See CMAT Statewide Operational Plan, at 70.



## 2. *The State Unduly Limits the Availability of Community-Based Services*

The State also places undue limits on the availability of community-based resources that could prevent entry into nursing facilities and allow children to remain in or return to the community. The State has implemented measures that have expanded nursing facility capacity, including an enhanced *per diem* rate for medically fragile children, while simultaneously limiting or reducing the availability of community-based care. Families who care for children with medically complex conditions in their homes reported frustrations with policies regarding home and community-based services, and, in particular, with the constant threat of service reductions.

For example, as described above, the State has established utilization review processes for certain in-home services. These processes require families of children receiving in-home services to recertify every six months that the services are medically necessary. However, on numerous occasions, the State has reduced or denied the availability of prescribed in-home services at these recertification periods, even where the child's condition and their families' ability to provide care had not changed. These reductions result in shifting care to the child's family, even though they may be unavailable or unable to safely provide the care the child needs. These families must then appeal the reductions in services, resulting in lengthy reconsideration and appeals processes that impinge on their ability to go to work, care for their children, and conduct other business of the family. A number of families who have been subject to repeated service reductions recently joined a lawsuit against State officials challenging these practices.<sup>37</sup> They allege that State policies and practices have led to repeated denials of medically necessary services, in violation of both the ADA and the Medicaid Act resulting in their children having to enter nursing facilities to receive necessary services.<sup>38</sup>

The United States Court of Appeals for the Eleventh Circuit has recognized that such practices may violate the EPSDT requirements of the Medicaid Act. See Moore ex. rel. Moore v. Reese, 637 F.3d 1220, 1259 (11th Cir. 2011) ("When a state Medicaid agency has exceeded the bounds of its authority by adopting an unreasonable definition of medical necessity or by failing to ensure that a required service is 'sufficient in amount, duration, and scope to reasonably achieve its purpose,' aggrieved Medicaid recipients have recourse in the courts.") On remand, a district court recently found the unreasonable application of policies aimed at shifting in-home skilled care to a child's caregivers violates the Medicaid Act's requirements that states must ensure the availability of medically necessary services for Medicaid-eligible children. See Moore ex rel. Moore v. Cook, 2012 WL 1380220, at \*10 (N.D. Ga. Apr. 20, 2012) ("I am convinced that the real reason for reducing [plaintiff's] nursing care hours was an unreasonable application of the [defendant's] policy to wean nursing care and shift more of the burden to her caregiver"). And in another case, the court found that such practices also violate the ADA. See Royal ex rel. Royal v. Moore, 2012 WL 2326115, at \*9 (N.D. Ga. Jun. 19, 2012) (holding State violated the ADA and the Medicaid Act where "the real reason [for the State's reduction in in-home nursing] was not due to an individualized determination of medical necessity, but due to [defendant's] policy and practice . . . to wean nursing care and to shift more of the burden of skilled care to [plaintiff's] parent caregiver over time").

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<sup>37</sup> See A.R. v. Dudek, No. 12-60460 (S.D. Fla., filed Mar. 13, 2012).

<sup>38</sup> See id.

Service limitations and reductions in the rates paid to providers of community-based care have also placed strains on families and providers. Families told us they are afraid that, over time, such measures will result in the admission of their children to nursing facilities or other institutional settings. On more than one occasion, we learned of families with one or more children or young adults with disabilities who have had to choose which of their children would live at home and which would live in an institution. Providers of community-based services and other stakeholders expressed similar concerns regarding the State's administration of these programs and the health and safety of recipients. One provider of community-based services informed us of at least two individuals who had previously been in their care with waiver-funded services and who were placed in a nursing facility because the State denied continued eligibility for the specific waiver-funded service.

These concerns also appear to be rooted in the State's policies and practices, which in recent years have led to reduced availability of home and community-based waiver programs. In the last several years, the number of individuals served through these programs has decreased, resulting in a growing list of children waiting years for services and having access to a waiver slot only once they have literally deteriorated to the point of "crisis." The State has also systematically reduced or rejected funding for community-based services—in 2011, for example, the State rejected nearly \$40 Million in federal dollars designated specifically to support individuals transitioning from nursing facilities and other institutional settings to the community.<sup>39</sup>

Although the State has added limitations or imposed restrictions on the availability of community-based care for children with disabilities, it has consistently raised the enhanced *per diem* rates offered to facilities housing children who have medically fragile conditions.<sup>40</sup> It has also ensured that nursing facilities seeking to serve more children can do so—in 2011, at the request of one nursing facility serving children, the State removed a regulatory limit that had previously limited the number of children served at a nursing facility to sixty.<sup>41</sup> In the wake of these changes, and in apparent response to increased need for facility services due to the lack of sufficient community alternatives, one facility administrator informed us of plans to open a sister

39 In early 2011, Florida applied for and received a \$37.5 million grant from the federal Centers for Medicare and Medicaid Services through the Money Follows the Person initiative, which funds support for individuals transitioning to the community from nursing facilities and other institutions. See generally, CMS Website, Money Follows the Person, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html> (last visited July 11, 2012). In June 2011 the Florida Joint Legislative Budget Commission voted to prevent the release of these funds. See Florida Joint Legislative Budget Commission, June 24 Meeting Packet, at 49, available at <http://www.leg.state.fl.us/Data/Committees/Joint/JLBC/Meetings/Packets/062411.pdf> (describing MFP grant and AHCA request for \$2 Million in funds to implement the grant); Florida Joint Legislative Budget Commission Report, at 13, available at <http://www.leg.state.fl.us/Data/Committees/Joint/JLBC/Actions/062411.pdf> (rejecting AHCA request); see also Linda Shrieves, Florida rejects millions more in federal health-care grants, Orlando Sentinel (Jun. 29, 2011), [http://articles.orlandosentinel.com/2011-06-29/health/os-florida-federal-grants-20110629\\_1\\_nursing-homes-federal-grant-money-on-nursing-home-care](http://articles.orlandosentinel.com/2011-06-29/health/os-florida-federal-grants-20110629_1_nursing-homes-federal-grant-money-on-nursing-home-care).

40 Since January 2005, the supplemental rate paid to facilities serving medically fragile children has increased by 23%. See AHCA Website, Nursing Home Supplemental Payments, [http://ahca.myflorida.com/Medicaid/cost\\_reim/nhsp.shtml](http://ahca.myflorida.com/Medicaid/cost_reim/nhsp.shtml) (last visited July 11, 2012).

41 See Fla. Admin. Code. R. 59A-4.1295(7)(e) (2010); Plantation Nursing & Rehab. Ctr. v. Agency for Health Care Administration, No. 10-10313RX, 2010 WL 5135584, at \*1 (Fla. Div. of Admin. Hearings, Dec. 14, 2010).

facility to child admissions to expand to a new area of the State. Another facility is undertaking a renovation and expansion in an effort to allow older children and teenagers to “age in place” in a ward with adults and elderly residents.

E. Serving Children Who Have Medically Complex or Medically Fragile Conditions Can Be Reasonably Accommodated In the Community

A state’s obligation to provide services in the most integrated setting may be excused only where a state can prove that the relief sought would result in a “fundamental alteration” of the state’s service system. Olmstead, 527 U.S. at 603-04. To invoke the fundamental alteration defense, a public entity must demonstrate that it has a “comprehensive, effectively working plan” in place to address unnecessary institutionalization. Olmstead, 527 U.S. at 605-06; Pa. Prot. & Advocacy, Inc. v. Pa. Dep’t of Pub. Welfare, 402 F.3d 374, 381-82 (3d Cir. 2005).

Here, providing children in nursing facilities opportunities to move to more integrated settings, and expanding and ensuring the sufficiency of services in the community, would not fundamentally alter the State’s service system and can be reasonably accommodated. As described above, the State is already obligated under the PASRR requirements of federal law to ensure individuals with disabilities are adequately screened before entry to a nursing facility to make a determination of whether community placement would be appropriate, and to identify specialized services that are needed. See 42 U.S.C. § 1396r(e)(7); 42 C.F.R. §§ 483.100 to 483.138. And the State is similarly obligated under the EPSDT requirements of the Medicaid Act to provide certain medically necessary services and currently makes other home and community-based services available through its Medicaid program. See 42 U.S.C. § 1396a(a)(43); 42 U.S.C. § 1396d(a)(4); 42 U.S.C. § 1396d(r)(1)-(5). Indeed, the State already makes available a range of services that enable children and young adults with medically complex conditions to remain at home with their families or in other integrated settings. Hundreds, if not thousands, of children with diagnoses and needs similar to those of currently institutionalized children receive services through these programs. However, as described above, the State limits the availability of or access to these services, often for reasons not based on medical necessity.

Moreover, a state cannot demonstrate a fundamental alteration exists unless it can show that it has developed and is implementing a comprehensive and effective plan to move individuals with disabilities into the community, with any waiting list for services moving at a reasonable pace. Olmstead, 527 U.S. at 584; Frederick L. v. Dept. of Pub. Welfare, 422 F.3d 151, 157 (3d Cir. 2005) (“[A] comprehensive working plan is a necessary component of a successful ‘fundamental alteration’ defense.”); Pa. Prot. & Advocacy, Inc. v. Dept. of Pub. Welfare, 402 F.3d 374, 381 (3d Cir. 2005) (“[T]he only sensible reading of the integration mandate consistent with the Court’s Olmstead opinion allows for a fundamental alteration defense only if the accused agency has developed and implemented a plan to come into compliance with the ADA.”)

During our investigation we found no evidence of a comprehensive, effectively working plan designed to reduce the State’s reliance on nursing facilities for individuals in this population. Instead, children and young adults languish for years in nursing facilities without meaningful opportunities to transition to more integrated settings. And for those individuals for whom waiver services may be appropriate, a growing waiting list of approximately 20,000 people and the State’s other policies significantly impede their ability to access community-based services.

## **V. RECOMMENDED REMEDIAL MEASURES**

The State should promptly implement a number of measures to remedy the deficiencies discussed above and protect the civil rights of children and young adults with disabilities who receive services in the State. The State must increase community capacity by allotting additional waiver slots, amending existing policies, and expanding other community services to serve children in or at risk of entering nursing facilities. The State must also amend policies that may lead to inappropriate denial of medically necessary services. The State should take all efforts to prevent new admissions of children and young adults to nursing facilities, including expanding or ensuring the sufficiency of community services necessary to support individuals in the community. If an individual is referred to CMAT for a recommendation of the appropriateness of nursing facility placement, the State must ensure that an adequate assessment is done to ensure that children with disabilities receive services in the most integrated setting appropriate to their needs.

The State must also implement a clear plan to ensure that children currently institutionalized in nursing facilities are provided the opportunity to receive services in more integrated settings. The State should take affirmative steps to develop an active transition plan that ensures that appropriate services and supports are in place to successfully serve children in the community, and that involves individuals knowledgeable about community living options and services to ensure that parents and guardians are fully informed of the community-based services available. The State cannot rely, as it currently does, on the staff of nursing facilities to locate and arrange for appropriate alternative services upon an individual's discharge. For those individuals whose families are unable to provide care for them in their own homes, the State must develop a process to clearly identify existing alternatives, including in medical foster care placements and other appropriate environments, that will meet the needs of the child.

For those individuals who currently live in, and those who have transitioned to, the community, the State must ensure that necessary services are delivered in a coordinated fashion, taking into account the needs and preferences of the child. Such service coordination should ensure that the child's medical, developmental, educational, and social needs are addressed with sufficient support to allow the child to succeed in a community-based setting.

## **VI. CONCLUSION**

Please note that this findings letter is a public document. It will be posted on the Civil Rights Division's website and we will provide a copy of this letter to any individual or entity upon request.

Please contact Travis England, the attorney assigned to this matter, at (202) 307-0663 within ten days to inform him whether the State is interested in working cooperatively with the Department of Justice to resolve this matter. In the event we determine that we cannot secure

compliance voluntarily to correct the deficiencies identified in this letter, the Attorney General may initiate a lawsuit pursuant to the ADA. See 42 U.S.C. § 12133; 42 U.S.C. § 2000d-1. We hope that you will give this letter careful consideration and that it will assist in remedying the State's failure to provide its services and programs for children and young adults with disabilities in the most integrated setting appropriate to their needs. If you have any questions regarding this letter, please call Gregory Friel, Acting Chief of the Civil Rights Division's Disability Rights Section, at (202) 307-0663.

Sincerely,

Thomas E. Perez  
Assistant Attorney General